

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



A Foundation
for Children
with Neurological
Impairment

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Children progress with home pc's

Dear Friends,

The mission of the Help a Little One Foundation is to brighten and improve the lives of children with neurological impairment.

Recently this has been achieved by continued gift-giving to those in pediatric residential communities, as well as giving support services to their families. Our efforts bring comfort to children and contribute to a stable and attentive family environment.

Family Circle support group is H.A.L.O.'s primary outreach mode to families of children with neurological impairment. Patty Reardon, our able and energetic social worker, educates parents on available services and problem-solving resources, and facilitates an empathetic social group. Additionally, and importantly, she alerts us to areas of need.

Technology is one of the most urgent needs for disabled children and their families. Today, children with many different challenges demonstrate progress beyond expectations when the correct technology is available and applied. That achievement is sustained when reinforced at home.

Home computers are still beyond the financial reach of many families, particularly those burdened with other expensive health care needs. H.A.L.O. has already provided three at-home computers with software this year to extend and support learning by children with special needs. These gifts also supply parents with convenient Internet access to research therapies, equipment and programs suited to their children's needs. We have highlighted one recipient on page three.

When you help even a little, you Help A Little One. When you Help A Little One, you help us all. As always, we thank you for your continued support and wish you health and happiness over the holiday period.

Sincerely yours,

Alan Pinshaw

A Foundation for Children with Neurological Impairment

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Cape Cod's "best beach" hosts educational adventures

EASTHAM, MA — Five residents from New England Pediatric Care (NEPC) spent four glorious June days and nights basking with their families on the sands of popular Coast Guard Beach on Cape Cod.

"It was a wonderful experience for the family members who joined their kids because we experienced much more than a (nursing home) visit," said Karen Salkins, mother of 22-year-old Jimmy. "It was great to stay overnight and sleep in the same place your kids are at," she said. "It's hard to be home every day, knowing you can't always see your child, even when you live only half an hour away."

Recreation Director Laura Pica enrolled NEPC in the National Park Services NEED (National Environmental Education) program. Selected residents, moms, dads and siblings, and up to ten staffers guided students through recycling lessons, spent sunsets on the beach and nights in the former U.S. Coast Guard surf-rescue station at one of the top ten ocean beaches named in a national survey.

"Our lessons focused on paper, plastic and aluminum cans. It was so successful we are trying to implement a low key program with cardboard and paper at NEPC," Laura said. "We are applying to bring a different group of children to Coast Guard next year to study biodiversity."

The National Park Service facility offers an adaptable dorm and kitchen on the first floor, with full wheelchair access, and upstairs rooms for families and staff members. NEPC brought along full medical and therapeutic staff so that



Jimmy and his family enjoyed a stay at the Coast Guard Beach house for educational field trips

families could safely take advantage of natural settings within the National Seashore, including paved paths to the marsh area, beach ramps and even a walking trail for

***"It was great . . . to
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the blind.

"It's so hard, especially at first, when you place a child in residential care," said Jimmy's mother. "This experience should help new families get peace of mind. They see the staff interacting with all the kids, no matter what level they are at. It should give them hope that there are places out there that really want to help give the kids as much experience in life as they can. They really do take care of them."

Her son Jimmy has been a resident at NEPC for 15 years. "It took me so long to accept the fact that he couldn't live with me, but I

realize now that if he did he probably wouldn't be here. (Residential life) is the best thing for him. He loved the trip, even just sitting outside. But if he didn't have the consistency in his care, he wouldn't be at the point where he could enjoy this change."

Naturally there are challenges to bringing children with disabilities to the beach. Staffers used a special beach chair with fat blow-up tires to move wheelchair-bound kids across the sand. They also had to bring medicine, mattresses and the ubiquitous bean bag chairs (for soft support) in addition to clothing, sheets and beach paraphernalia. Schedules were adjusted and plenty of personal time was donated.

"It was worth all the effort," said NEPC's Laura. "We are always looking for opportunities to expand the horizons of our kids and we will be as creative as we need to be to provide quality experiences such as Coast Guard Beach."

Fernando's home computer opens doors to 'possibilities'

Figment ® the purple dragon encourages visitors to think about 'the possibilities' at Epcot Center's futuristic *Journey into Imagination* ® pavilion in Orlando, Florida.

David Kaloupek, co-founder of *healthycommunitiesonline.com*, and a team of educators at the Northeast Elementary School in Waltham, Massachusetts have done just that for nine-year-old-Fernando Valdes, a fourth grader with multiple challenges.

With support from the Help A Little One Foundation, this team has "imagineered" a home computer for Fernando, giving him the means to travel beyond his wheelchair and speech difficulties into a realm of 'possibilities.'

"Fernando has been with us since kindergarten," said Assistant Principal Diane Krueger. "He is a spunky little guy who is willing to try anything. He has amazing strength, and is especially insistent about moving independently since his spinal surgery this summer."

The PC (personal computer) is the best tool for Fernando, Diane said, because it enables him to complete school assignments, research and prepare presentations and keep pace with the rest of the class. The Communication Enhancement Center at Children's Hospital in Boston highlighted Fernando's need several years ago, "and the necessary equipment is provided for Fernando's use in school but public school hands are tied in acquiring materials to sup-

port students outside of school," she said.

Home support is vital because Grade 4 transitions from oral primary grade lessons to a curriculum heavy in writing skills, according to Fran Ferranti, Fernando's teacher. Typing is taught in class, and Fernando is managing well, she said.



From left: Teacher Aide Arlene Young Assistant Principal Diane Krueger and Grade 4 Teacher Fran Ferranti are dedicated to Fernando Valdes' success.

"David made the home-school connection possible by getting the support of the (H.A.L.O.) Foundation," said Diane, the Assistant Principal. "He brought all the pieces together."

"We are a non-profit focused on helping people use the computer and the Internet to manage and overcome the challenges presented by disability and disease," David explained. Efforts have been limited due to the economic slowdown in Massachusetts, but he is establishing pilot projects in partnership with local schools, housing authorities and nursing homes in Waltham.

David learned of Fernando's need earlier this year through Community Policing Officer June Con-

way, who has connected with residents at the Chesterbrook complex, where Fernando, his mother Edna, and sister Ketsy reside.

"We saw a bright, motivated young man with neuromuscular problems, who could benefit enormously from using a computer and the Internet, David said. "In addition, we think it's a good investment in this entire family. Computers and the Internet are resources for all of us to learn, to maintain contact with other people, to communicate and to find information."

As Fernando gets older these skills will give him and his family more options for independence, said David. Already, Fernando reports that Ketsy is angling for more time at the keyboard (she's a student at Kennedy Middle School), and Edna is

scheduling tutoring time to upgrade secretarial skills she practiced before Fernando's birth.

The most appropriate software for Fernando is available only for a PC, so the school staff is arranging access to a PC in place of the Macintosh available in elementary classrooms. Diane said the compatibility will increase his ability to participate.

David is working with the local cable company to bring high speed Internet service to Chesterbrook.

It is slow going, but H.A.L.O., David and the Northeast School team are determined to give Fernando, his mother, and sister the tools to explore all of those 'possibilities.'

Challenger division means



Community members coach and assist in the fun at Challenger Flag Football.

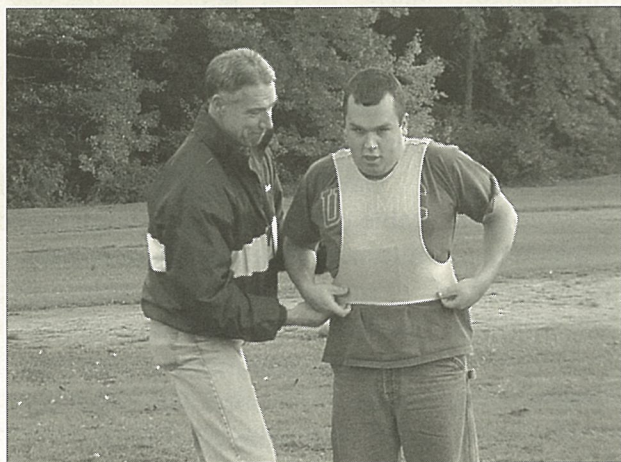
Everybody wins in Challenger Division Little League . . . and Challenger Flag Football . . . and Challenger Basketball in Norwood, Massachusetts.

Coaches Bob Smith and Rick Reardon and 25 to 40 other volunteers work hard to ensure that boys and girls with disabilities, their Moms, Dads, brothers and sisters, and big-hearted high school kids and others in the community feel like winners all season.

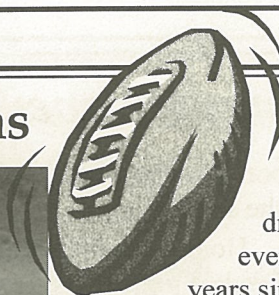
The team participants have disabilities that hold them back in competitive sports leagues: Down Syndrome, neurological impairment, or a variety of conditions that limit participation on standard teams.

"We give them uniforms and a sense of belonging," Bob said. "The team concept is important. They may never get to wear another uniform."

Sue Morse, another Norwood parent, started the league in 1993 to provide a winning sports experience



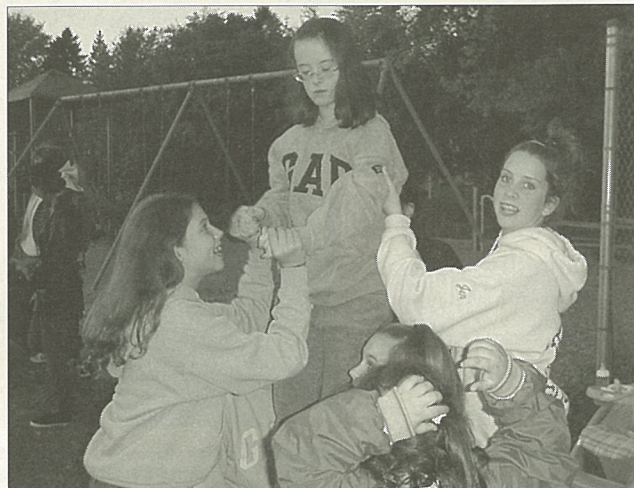
Bob Smith, left, organizes Challenger baseball, basketball and flag football teams.



everybody wins

for the kids. Families have turned out in droves to support it. Parents joke that every team has been undefeated in the ten years since the league's inception, even when they play each other, Bob said.

The first newspaper ad for an official Challenger Little League team drew 18 kids. Word spread quickly through the Boston suburbs. Now 65 boys and girls from Attleboro to Newton to Weymouth and beyond play on six baseball teams. In September and October about 45 challenged children gather for football; December through March they flock to donated gyms for basketball. Teens organize cheerleading squads, too.



Dozens of high school students volunteer at Challenger games.

Bob, an AMTRAK police officer, modestly declines credit for the many hours he devotes to reserving fields, lining up volunteers and preparing for the annual "under the lights" games, but parents sing his praises.

"I don't know what we would do without Bob," said Donna, one of a group of mothers (they call themselves "The Three Musketeers") cheering on flag football players on a recent October night.

"It means a lot not only to the kids, but to us as parents, that our child can belong, have friends, have something to talk about at school," she said.

Another mother, whose son has played on teams for seven years, was appreciative of the opportunity to meet parents of other children with similar challenges. "We share our experiences. We support each other."

"This gives our kids a sense of worth," said another parent. "My son talks about playing for BC (Boston College) some day. I know it's not going to happen, but it's that real for him. Our kids dream just like other kids."